Remarks of HENRY A. WAXMAN, Chairman,

Subcommittee on Health and the Environment before

The National Lesbian and Gay Health Conference March 28, 1987

I'm glad to be here with you tonight. This is my home town. Let me belatedly welcome you to it and say that we are honored and pleased to have you here. The breadth of your agenda and the credentials of your participants demonstrate that the lesbian and gay health movement is a serious participant in health policy. The by-now well-known dedication of providers of services to lesbians and gay men has long demonstrated that you are the best resource in a health care system that is often filled with discrimination and neglect.

It is particularly appropriate for this meeting to be in L.A. and coordinated through the Gay and Lesbian Community Services Center. It was here—five years ago next week—that the Health Subcommittee I chair held the first Congressional hearing on what was known as Kaposi's Sarcoma and Related Infections. There were then three hundred cases reported and 123 deaths.

The hearing was held in the Center. Three reporters came.

It seems like a lifetime ago.

No Word from the President

Since that time there have been thousands of deaths. But still no word from the President.

There have been tens of thousands of cases. But still no word from the President.

There have been millions of infections. But still no word from the President.

There have been hearings, debates, budgets, legislation, plans, lawsuits, ballot initiatives, and <u>thousands</u> of reporters. But still no word from the President.

The first message I want to give you tonight is that we should neither forgive nor forget.

Don't let the President off now because he is no longer proposing cuts in AIDS budgets. Don't give the President the credit for Dr. Koop's report when no dollars or dedication follow it.

True--we must work with the Administration. Its positions and endorsements hold great power.

But this President should not be remembered for the Tax Bill or Star Wars or for Iran and Nicaraqua.

He must be remembered as the President who allowed thousands to die and allowed the Nation to be frightened and torn apart. He must be remembered as showing <u>less</u> foresight with <u>more</u> information than any leader since Herbert Hoover or Neville Chamberlain.

Don't forgive.... Don't forget.

Not the Usual AIDS speech

Having said that, I don't want to give you just another speech about the epidemic.

You know the numbers. I know the numbers. You know that I know the numbers.

I won't describe the cost or the tragedy of the disease. You know these things. I know these things.

I support confidentiality of counseling and testing. I support Federal protections against discrimination. I will work for early passage of such legislation. You will, too.

I give a lot of AIDS speeches to straight audiences. I speak to medical groups, to pharmaceutical executives, to insurance lobbies, to investment bankers, to Congressmen, and to the press--and no matter what they've asked me to discuss, I also talk about AIDS.

You don't need to hear these things. I'd like to spend some time tonight talking to the Lesbian and Gay Health Conference about broad health issues—of which AIDS is a part. The epidemic is so overwhelming that many of you have professional and personal lives that allow no time for anything else.

AIDS shows the failure of American health care

But although it is unique in some ways, AIDS has only shown in harsh light the cracks and flaws and holes in the American health care system. It is a crystallization of the worst problems in preventing illness and caring for the sick.

- * AIDS has shown that our insurance system is unfair. If you lose your job--because of economics or because of illness--you lose your insurance.
- * AIDS has shown that Medicaid is shallow and inadequate. Many middle-class Americans are learning the hard way that in most States you can qualify only if you're totally disabled and have less than \$1,500 to your name.

- * AIDS has shown that we can produce medical miracles for the rich and plain neglect for the poor. AZT is priced for kings and Medicaid is for people who have been made paupers.
- * AIDS has shown that our best private hospitals are basically businesses--dumping patients without insurance.
- * And AIDS has shown that our public hospitals are crowded, understaffed, underequipped, and bankrupt.

These failures, however, are not unique to AIDS. AIDS has only shown them in bold relief.

Two Lessons--First Take Care of AIDS Patients as Part of Broken System

This leads me to say that you have two tasks now: First, to take care of AIDS patients within this broken system. And second, to fix the system for all Americans.

Clearly you know a lot about taking care of people. Nationwide, clinics like the Edelman Center and programs like AIDS Project L.A. have provided services when local, State, and Federal governments have abdicated their responsibilities. In many ways, PWA's--primarily because of you and others like you--are better served than most other catastrophically ill Americans.

But the numbers are going to become overwhelming. And while we have become accomplished at resisting the attacks of ideologues and evangelists, we must also be prepared to resist the seductions of con artists and snake oil salesmen. Our enemies come dressed in sheep's clothing as well as in that of wolves. PWA's and the people who care for them must become the sophisticated consumers of health care that many elderly and disabled people have become.

This is a saddening realization, because it is an implicit statement that AIDS is not just an emergency that will be dealt with and be over. AIDS is not just a public health drama played on a political stage.

It is also daily life--tedious, mundane, maddeningly slow, and detailed. It is not just getting a drug approved, but paying for it. It is not just getting insurance, but also understanding deductibles. It is not just signing up for research, but getting fully informed consent.

You, as health professionals, understand this best. You have lived with the epidemic not just as a catastrophe, but as your daily work.

Second, Fix the System to Care for Everyone

As difficult as this first task is, the second is even more so.

Many gay people have become assimilated into mainstream society. As this has happened, gay concerns have become not just sexual politics, but budget politics, electoral politics, and foreign politics. People have stopped worrying about closets and started worrying about tax shelters or about shelters for the homeless, depending upon your party and your social class.

In the same way, as AIDS becomes more assimilated into medicine and health care, health professionals will have to manage the enormity of the epidemic while still caring for the other sick and disabled of society. Even those most concerned for PWA's and the special tragedy of AIDS will have to deal with the routine of keeping the health system functional.

We must hope that when we win the battle to have AIDS recognized as an illness and not a curse and to have PWA's recognized as people and not as victims—at that time we must hope that AIDS professionals and AIDS patients continue to care for others as well as for each other.

If there's a lesson that AIDS has made clear to PWA's and to health care providers, it is that we cannot have a health care system that is "Every Man For Himself."

Today, AIDS organizations are able to rally celebrity support. You have fund-raising ability. But other single-issue health care groups have found such support fleeting and eventually not solid. The halls of Congress are filled with disease societies and disability foundations. None of them has made the system better for more than a moment for more than a few.

As the costs of the epidemic mount, such a unilateral approach could lead to forced choices--pay for AZT or for prenatal care. Pay for nursing home beds for PWA's or for the retarded. Do research on AIDS or on Alzheimer's.

Or, most dangerously, expand Medicaid or lower taxes.

Such fighting over slices of a small, badly made pie will help no one.

If we allow the Reagan Meanness to divide PWA's and those that care for them from other disabled and sick and disenfranchised people, then the Reagan Meanness will have divided and conquered us all. Instead, we must use the hard-won wisdom of AIDS to re-make this health care system into one that cares for the sick and prevents illness.

If we do less, then we will have to say that nineteen thousand people have died in vain.

If we can achieve this, we can know that they did not. I look forward to working with you to prove that.

Thank you.